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Need Assessment for Individuals with Severe Mental Illness at Community Mental Health Units in Greece; Presence and Severity of Needs.

Master's Dissertation in **International Mental Health Policy and Services**

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ABSTRACT

The aim of the study was to conduct a need assessment in individuals with a SMI who use a wide range of mental health services with a specific focus on community mental health units in Greece. The research took place with the cooperation of EPAPSY which is a major NGO in Greece and the University clinic of Eginition (inpatient and outpatient units). The main research instrument was the CAN-R which has been adapted to the Greek population by Stefanatou et al. (2014). No other need assessment research in mental health has been conducted previously. Our sample (N=111) included a wide range of community mental health units in different regions of Greece. Along with the CAN we used PANSS for symptom severity, WHODAS 2.0 for functionality and WHOQOL-BREF for quality of life. The current study has focused on the profiling of needs of individuals with SMI calculating the level of agreement between users and staff members, as well as depicting the presence of need. In our study the level of agreement of staff members was in concordance with mental health service users while several needs were identified in line with international evidence. Namely, accommodation, psychotic symptoms, psychological distress and intimate relationships were identified. Intimate relationships, company and sexual expression were identified as serious unmet needs. A major discrepancy between staff members and users was noted in the psychological distress field. Users tend to identify as a serious unmet need the psychological distress (19.8%) while the staff considered this need as unmet only in the 10.8% of the cases. We are hoping to further process the correlations between PANSS, WHODAS 2.0 and WHOQOL-BREF to provide evidence in transforming services to meet self-reported needs in mental health service users in Greece.

Keywords: *needs assessment, profile of needs, staff member and user agreement*

RESUMO

O objetivo do presente estudo foi o de realizar uma avaliação das necessidades de indivíduos com doença mental severa (SMI), utilizadores de diversos serviços de saúde mental, e com especial foco nas unidades de saúde mental comunitária na Grécia. O estudo foi realizado em cooperação com a EPAPSY, que é uma importante ONG na Grécia, e a clínica da Universidade de Eginition (com unidades de internamento e de ambulatório). O principal instrumento de investigação utilizado foi o CAN-R, que foi adaptado para a população Grega por Stefanatou et al. (2014). Nenhuma outra avaliação de necessidades em saúde mental foi até então realizada. A amostra em estudo (N = 111) abrangeu um vasto número de pessoas de unidades de saúde mental comunitária de diversas regiões da Grécia. Além do instrumento CAN, foi também utilizado o PANSS para avaliar a severidade dos sintomas, o WHODAS 2.0 para avaliar a funcionalidade e o WHOQOL-BREF para avaliar a qualidade de vida. O estudo centrou-se na definição do perfil das necessidades dos indivíduos com doença mental severa através do cálculo do nível de concordância entre os utilizadores dos serviços e os profissionais de saúde, bem como na descrição da presença da necessidade. Neste estudo, observou-se um elevado grau de concordância das necessidades entre utilizadores e profissionais de saúde mental, e as necessidades identificadas estão de acordo com a evidência internacional. As necessidades identificadas foram nomeadamente o alojamento, a sintomatologia psicótica, o sofrimento psicológico e os relacionamentos íntimos. Os relacionamentos íntimos, a interação social e a expressão sexual foram identificadas como as necessidades não satisfeitas mais graves. A maior discrepância da concordância entre funcionários dos serviços e utilizadores foi observada ao nível do sofrimento psicológico. Os utilizadores dos serviços tendem a relatar que o apoio ao sofrimento psicológico é uma necessidade não satisfeita grave (19,8%), enquanto os profissionais tendem a considerar que essa necessidade só não é colmatada em apenas 10,8% dos casos. No futuro, espera-se recorrer às correlações entre os dados do PANSS, WHODAS 2.0 e do WHOQOL-BREF para fornecer informação adicional necessária para o desenvolvimento de serviços que colmatem as reais necessidades de saúde mental dos seus utilizadores na Grécia.

Palavras-chave: avaliação de necessidades, perfil de necessidades, concordância entre utilizadores e profissionais de saúde.

RESUMEN

El objetivo del estudio fue realizar una evaluación de las necesidades de los individuos con un SMI que utilizan una amplia gama de servicios de salud mental con un enfoque específico en las unidades de salud mental de la comunidad en Grecia. La investigación se llevó a cabo con la colaboración de la EPAPSY, que es una major ONG en Grecia y la Clínica Universitaria de Eginition (unidades de pacientes internos y externos). El instrumento principal de la investigación fue el CAN-R que ha sido adaptada a la población griega por Stefanatou et al. (2014). Ninguna otra investigación evaluación de las necesidades en materia de salud mental ha sido llevada a cabo con anterioridad. La muestra (N = 111) incluye una amplia gama de unidades de salud mental de la comunidad en las diferentes regiones de Grecia. Junto con la CAN se utilizó la PANSS para la gravedad de los síntomas, WHODAS 2.0 para la funcionalidad y el WHOQOL-BREF para la calidad de vida. El presente estudio se ha centrado en la elaboración de perfiles de las necesidades de las personas con SMI calcular el nivel de acuerdo entre los usuarios y los miembros del personal, así como que representa la presencia de necesidad. En nuestro estudio el nivel de acuerdo de los miembros del personal era en concordancia con los usuarios del servicio de salud mental mientras que varias necesidades se identificaron en línea con la evidencia internacional. A saber, el alojamiento, los síntomas psicóticos, trastornos psicológicos y las relaciones íntimas se identificaron. Las relaciones íntimas, la empresa y la expresión sexual fueron identificados como necesidades insatisfechas. Una de las principales discrepancias entre los miembros del personal y los usuarios se observó en el campo de los trastornos psicológicos. Los usuarios tienden a identificarse como un serio insatisfecha necesita el trastorno psicológico (19,8%), mientras que el personal considera esta necesidad como no satisfecha tan sólo en el 10,8% de los casos. Estamos esperando para seguir transformando las correlaciones entre la PANSS, WHODAS 2.0 y WHOQOL-BREF para proporcionar evidencia en la transformación de los servicios para satisfacer las necesidades de la percepción subjetiva de los usuarios de servicios de salud mental en Grecia.

Palabras clave: *evaluación de las necesidades, el perfil de las necesidades, miembro del personal y del acuerdo con usuario*

Contents

Acronyms used in text

EPAPSY	[Greek] Etairia Perifereiakis Anaptixis kai Psychikis Ygeias (Association for Regional Development and Mental Health)
WHO	World Health Organization
PSR	Psychosocial Rehabilitation
SMI	Serious Mental Illness
IKA	[Greek] Idryma Koinonikon Asfaliseon (Social Security Fund)
MHU	Mental Health Unit
CAN	Camberwell Assessment of Need
WHOQoL-BREF	World Health Organization Quality of Life – Brief
WHODAS	World Health Organization Disability Assessment Schedule
PANSS	Positive and Negative Syndrome Scale
ICC	Intra-Class Correlation
ICD - 10	International Classification of Diseases
ICDIDH	International Classification of Impairments, Disabilities and Handicaps
DALY	Disability-Adjusted Life Year
KOISPE	[in Greek] Koinonikos Synetairismos Periorismenis Euthinis (Social Cooperative)

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Part I – Background

1. Introduction

Mental health service evaluation is a critical issue of mental health care. It has also been raised as a question in psychiatric reform as a quality assurance necessity. World Health Organization (2003, p.12) refers to quality assurance as *"the traditional approach to monitoring quality [...] which involves the development of a set of service standards, and the comparison of current services with the established standards. If standards are met, services are thought to be of adequate quality. If deficiencies are identified, plans of correction are developed to address the problem"*. Mental health care has been shifting from traditional hospital-centered care to community-based mental health care. The process of transforming mental health care to a more community oriented approach demands that we are based on (1) ethics, (2) evidence and (3) experience involving users and their subjective experience as "*the best experts*" (Graham Thornicroft, Tansella, & Law, 2008).

Psychosocial Rehabilitation has largely contributed to the abovementioned reform from Asylum care to Community based care. According to the consensus statement of the World Health Organization and the World Association for Psychosocial Rehabilitation (World Health Organization & World Association for Psychosocial Rehabilitation, 1996), Psychosocial Rehabilitation (PSR)
"is a process that facilitates the opportunity for individuals – who are impaired, disabled or handicapped by a mental disorder – to reach their optimal level of independent functioning in the community". Spaniol, Wewiorski, Gagne, & Anthony, (2002) define the mission of PSR as helping individuals with psychiatric disabilities increase their ability to function successfully and to be satisfied in the environments of their choice with the least amount of ongoing professional intervention. The above should be the basis when considering PRS strategies at a state level. Greece, in particular has already integrated the above statements in the legal framework of the Psychiatric Reform (Law 2716/99).

Saraceno (2007) argues that a necessary requirement to provide high standard mental health treatment and care is "the adoption of an integrated system of service delivery which attempts to address comprehensively the full range of psychosocial needs of people with mental disorder".

The goals that are set for such an integrated system are thus "1) shifting care away from large psychiatric hospitals, 2) developing community mental health services and 3) integrating mental health care into general health services".

Continuous evaluation includes the establishment of evaluation indicators in order to further improve the sensitivity of the mental health care system to the changing needs of the users and their carers shifting care to the integration of mental health services in the community. The evaluation of quality should be based on structure, process and outcome indicators. Although structure, process and outcome components are all types of measures in quality work, it is important to discern the differences between them once the structure refers to the physical equipment and facilities, process refers to the ways the system works and outcome focuses on the results and if the intervention/services make a difference for the user.

Among the main concerns of the psychiatric reform and the functioning of the mental health care system is to evaluate how the services are provided. Systematic needs assessment has been underlined as an important factor in the evaluation of mental health services which provides results on adequacy and effectiveness of therapeutic interventions (M Slade, Leese, Taylor, & Thornicroft, 1999). A retrospective evaluation, ("ex-post evaluation"), of the implementation of the "National Action Plan Psychargos 2000-2010" of the psychiatric reforms was commissioned at the end of 2010 by the Greek Ministry of Health answering the request of the European Union(Greek Ministry of Health and Social Solidarity, 2010). Among the main weaknesses of the Greek Psychiatric Reform it was shown that there was *"(b) a lack of a population-based approach to the mental health system, without clear evidence for assessing the needs of local populations and no clear understanding at the local level of what components are necessary for a comprehensive system of care"* while the evaluation also showed that there were no quality assurance mechanisms and systems for clinical governance. As far as user participation is concerned it was argued that service users' involvement and carer advocacy *"remained underdeveloped despite some progress and the fact that there are some organisations in place"* (Loukidou et al., 2013). Consequently, as Slade & McCrone (2001) suggest need assessment is expected to largely contribute the rational and efficient use of the limited resources in order to develop appropriate interventions to cover the needs of

mental health service users while also enhance their quality of life(Antonio Lasalvia et al., 2005). Wiersma(2006, p. 116) defines need as *"the psychological or social dysfunction as a consequence of mental illness"*. From the public health point of view though Andrew Stevens (1994) refers to the need as the ability to benefit from healthcare services. This entails treatment, prevention, diagnosis, continuing care, rehabilitation or palliative care as Wiersma (2006) clarifies and re-defines care as *"the necessity of an effective intervention as defined by a professional; a demand is the expression of a wish to use care (or a willingness to pay for) and utilization is the actual use or consumption of provided health care"*.

Moving toward the values of recovery and user-led services, it is of great importance to assess the needs of mental health service users and transform services to suit those needs (Fleury, Grenier, Caron, & Lesage, 2008). Thornicroft and Tansella (2005) argue that community-based mental health services "should be established upon the foundation of nine guiding principles: autonomy, continuity, effectiveness, accessibility, comprehensiveness, equity, accountability, co-ordination, and efficiency" stressing out the vital importance of user involvement in defining the aforementioned principles and in developing "methods of monitoring how far mental health services pay sufficient respect to these principles".

1.1 Evaluation of Community Mental Health Services

Patton (1997) defines evaluation as *"the systematic collection of information about the activities, characteristics and outcomes of programs to make judgments about the program, improve program effectiveness, and/or inform decisions about future programming"*. Health Service Evaluation has two fields of implementation: the evaluation of clinical – therapeutic programs and the evaluation of services or the wider health system. The term "*evaluation*" is the common denominator for a wide range of approaches that *"... include the assessment of user needs and the planning of services, national health policy directions, specialized response and programme assessment studies, methodological proposals and practices, research on the users' views and satisfaction and specialists' attitudes, ways of clinical activity documentation, expenses and, finally, the rehabilitation activity assessment"*(Rossi, 1994).

It is important to point out that mental health care differs from physical health care since the needs that psychiatric disability poses are more complex than the needs posed by physical illness. The aforementioned gap grows even more if we consider the subjective reality of "suffering individual", the "mental suffering" and the complexity of the social networks and the quality of life(Stylianidis & Ghionakis, 1996). Mental health care should thus be based on the needs of the service users at a context of needs-led services. Macpherson, Varah, Summerfield, Foy, & Slade, (2003)argue that *"individuals accounts of their own needs are likely to ensure up to date information and allow correct definition of personal needs"*.

The research on recovery proves to be very useful at this point since it places the importance on the subjective perception of self and thus the needs that an individual can express. There is also evidence that Recovery-oriented services are providing more satisfactory care to the users (Shepherd, Boardman, & Slade, 2008) and there also been evidence that it has an impact on quality of life as well as community integration. The recovery movement as described by Mike Slade, (2009) has moved the balance to the "subjective experience of the individual" rather than on national systems. Burns (2014)emphasizes the *"central importance of choice and personal satisfaction balanced against the professionals' desire to cure".*

Monitoring and evaluation is an integral part of planning and materializing community mental health services (Tansella & Thornicroft 2001, Thornicroft & Tansella 1999). It is of central importance to establishing a large and sound body of evidence that will support mental health service provision and ensure that services are needs-led and not developed randomly as has been the case with Greek Mental Health Reform. As Stylianidis and Chondros (2016) point out "one key mistake of the Greek Psychiatric Reform is the fragmentation of the system and the unequal allocation of services. Mental health services are provided by the NHS (psychiatric hospitals, general hospitals, and various bodies governed by private law), the private sector, insurance providers such as the "IKA" social security fund, and local government agencies, military agencies, as well as by the Ministry of Education and by the Church". The above constitute a mental health system which lacks central coordination and thus according to Thornicroft, Tansella & Law (2008) such a mental health system lacking coordination and the ability to attribute responsibility becomes an ineffective, non-accessible and costly system.

The mental health action plan for the continuation of Psychiatric Reform in Greece considered the aforementioned arguments and supported the design of a unified "mental health system", whose main goal would be the integration of mental health units into one set unit *"that will address the needs of the population of the region and will include mechanisms of control and revision sensitive to changing needs, identified by epidemiological trends. The detailed documentation of standards and objectives, with certain milestones, forms a mechanism for continuous assessments, in order to optimize system performance and sensitivity to changing needs".*

1.2 Community Mental Health Service Evaluation: Questions of Psychiatric Reform

The main questions of psychiatric reform and the functioning of a mental health system are the following as they were formulated by Stylianidis, Skapinakis, Mavreas, & Lavdas (2014):

Who are the services for? The question refers to the population of individuals with a need for psychiatric care. The answer to such a question comes from epidemiological research in the general population observing both the treated (individuals with psychiatric disorders using psychiatric services) and untreated morbidity (individuals with psychiatric problems who do not use psychiatric services). In Greece, the only country-wide general population research of this kind was conducted in 2009 and its first results have already been published (Skapinakis et al., 2013).

Who provides the services? This question refers to the bodies and institutions providing psychiatric services.

- Psychiatric Hospitals
- Psychiatric Departments at General Hospitals
- Community Mental Health Centers
- Outpatient Clinics
- Psychosocial Rehabilitation Units
    - Day Care Centers
    - Residential Units(Hostels, Long Term Houses, Independent Living Supported Apartments)

- Special programmes and services (special clinics, Mobile Mental Health Units, special treatment programmes, etc.).

3. **How are the services provided?** This pertains to the available effective interventions by the MHUs. As Stylianidis, Mavreas, Skapinakis and Lavdas (2016) continue the main questions that seek answers are the following concerning this issue:
   a) *What are the necessary interventions for mental health problems?* In this case, the answer requires the presence or establishment of Clinical Guidelines on the basis of indications of their effectiveness, using the Evidence Based criteria.
   b) *Which interventions are available from psychiatric services?* The necessary data pertain to information on staff training and skills, as well as the use of interventions provided by the MHUs.
   c) *How satisfactorily are patient needs met by the services?*

   Depending on the level of needs met by the service, we have:

– **Needs that are not met:** These are needs for which there are effective interventions, but that the MHU is unable to cover for various reasons (lack of training, specialized staff, lack of time, etc.)

– **Needs that are met:** These are the needs that the service covers satisfactorily, either in full or in part. In the case of a need covered in part, the ensuing questions pertain to the capability of full cover and the reasons and shortcomings on which the part cover is due.

– **Needs that are met in excess:** These are needs that do not exist, but may have existed in the past and which the MHU continues to provide cover for, whereas it should have either discontinued or stopped the provision (e.g. maintaining the administration of a high neuroleptic medication dosage for patients over long time periods without due reason, providing housing to individuals who can be accepted back into the family home etc.).

4. **How effectively are the services provided?** This pertains to the evaluation of services and interventions. The question above refers to the regular maintenance of information about the patient and the therapeutic interventions. Such information includes:
   - *Personal details* (personal and family history, history of the disease, psychopathology and functionality)
   - *Socio-demographic details*

- *Basic details* on the patient's treatment or intervention and follow-up.

5. **What is the quality of the provided services?** The question pertains to the services' quality assurance. As there are no criteria pertaining to conditions in Greece, a study needs to be made of the international criteria, which can be adapted to the reality in Greece with the appropriate methodology.
6. **How satisfactorily are the services provided?** Satisfaction with services is of crucial importance in research and evaluation since it represents an integral component of the users' perspective in outcome assessment (Ruggeri et al., 2007).
7. **What is the attitude of the population about the services?** Research of the community's attitude is deemed necessary as the success of the mental health system depends on them, as well as its acceptability by the general population, and it gives vital information in planning services.
8. **How are the services being provided at a financial level?** This refers to the financial evaluation that is related to the efficiency of the service (or the health system).

a) *Cost analysis:* Cost is calculated in the monetary units that a disease or group of diseases (e.g. mental diseases) has for society. Direct costs (public or individual), loss of resources (for society, the individual and the family) and the transfer of resources from other sectors, are also taken into account.

b) *Cost/benefit analysis:* Is the systematic comparison in monetary units of all costs and the benefit of suggested alternative schemas, with a final investigation; first, of the degree to which this combination of schemas will achieve their set targets with a set financial investment; and second, the extent of the benefit that arises from the schemas (programmes, services, treatments) requiring a minimum investment.

c) *Cost/effectiveness analysis:* It is the same as the one above, except it measures the benefit in achieved results (e.g. days of work in rehabilitation programme, days of stay in the community without hospitalization etc.).

A major issue that should not be left out of the "financial question" refers to the importance of protecting the "budget for mental health" especially in a process of implementing changes dictated by the above key questions. Additionally, as Thornicroft, Tansella & Law (2008) point out *"having a protected budget is necessary but not sufficient, as it is also vital to be able to exercise flexibility within the overall budget, typically to re-use money saved by reducing the use of inpatient beds for community*

mental health teams, or occupational or residential services". In other words, financial resources should follow the user at all times to avoid diversion of those resources to other health sectors.

1.3 Remarks on the evaluation of mental health systems

Moving to a community-oriented mental health service provision, service user involvement in both planning and providing those services has been a growing concern internationally. The argument to involve users and develop services with them is both ethical as well as evidence based. There is emerging evidence that service users *"can make essential contributions to mental health. Outcomes data rated by service users in some cases are more important than those rated by staff"* as Thornicroft and Tansella argue (2005). The same authors () emphasize on the importance of mapping all available resources as well as their perspective in different dimensions to help develop needs-led services and indicate the necessary steps for their implementation. Two dimensions were conceived in the "matrix model" which was developed by Thornicroft and Tansella aimed to help assess *"the relative strengths and weaknesses of local services and to formulate a clear plan of action to improve them".* As we can observe in the model two dimensions were used; place and time. Place refers to geographical levels: 1) country/regional, 2) local and 3) individual. As for the second dimension of time, 3 phases were included; a) inputs, b) processes and c) outcomes. Mapping available resources locally and relating them to a regional/national level helps the continuity of services and the cohesion of the mental health system to maximize the offered services to the community and the individual. In the authors' words "The matrix model can assist, in a sense, the accurate diagnosis of dysfunctional mental health services so that corrective action can be applied at the right level(s) to improve care". Growing evidence (Slade et al., 1998; Hansson et al., 2001, Stefanatou et al., 2014) shows that users' needs are a strong criterion of outcome in order to develop or shape services to treat those needs.

1.4 Scope of the Research

Until recently there has never been a needs assessment research in Greece using standardized instruments. The Greek translation of CAN-R 3.0 was developed by Papageorgiou, Simos & Dimitriou (1996) but its' psychometric properties were not examined until 2013. Stefanatou, Giannouli, Konstantakopoulos, Vitoratou, &

Mavreas (2014)validated the Camberwell Assessment of Need (CAN) instrument for use in the Greek population to assess patients' clinical and social needs as well as fundamental human needs. The reliability (inter-rater and test-retest) as well as the concurrent/convergent validity of the Greek version of CAN-R was evaluated and the results for the 22 individual items and the eight summary scores of the instrument's four sections were good to excellent. Additionally, as the researchers continue significant correlations emerged between CAN scores and the WHOQoL-BREF and WHODAS 2.0 fields concerning both user and staff ratings, indicating good concurrent validity. Staff and patient views were recorded separately through structured interviews. This was the first CAN-R study with satisfactory results on needs assessment in mental health in Greece and thus it is crucial that we build on the evidence for met and unmet needs in this field. The CAN (Phelan et al., 1995) is one of the most commonly used instruments for need assessment and has been repeatedly used in numerous research works (Simons & Petch, 2002; Slade, Phelan, Thornicroft, & Parkman, 1996; Stefanatou, Giannouli, Konstantakopoulos, Vitoratou, & Mavreas, 2014; Wennström, Berglund, Lindbäck, & Wiesel, 2008). At this research we replicated the research protocol of Stefanatou, Giannouli, Konstantakopoulos, Vitoratou & Mavreas (2014) and we expanded the sample to a larger number of users and staff throughout Greece. The aim of our study was to assess the profile of needs of service users at a wide range of mental health services focusing on community mental health units as well as expand geographically the sample to include Central and Northern Greece. Also, a main aspect of our focus was to assess the level of agreement between users and staff in the aforementioned services which should work in a continuum of care and be able to understand the users' needs in order to adapt the provided services accordingly.

1.5 Need Assessment of users and professionals using CAN

CAN instrument provided the ability to challenge the traditional biomedical attitude that only mental health professionals can accurately assess the needs of the mental health service users. The innovation was in line with the shift towards a more bio-psychosocial model of care which was community-based. The first studies conducted by the authors of CAN as well as later studies from different researchers (Lasalvia, Ruggeri, Mazzi, & Dall'Agnola, 2000; Ochoa et al., 2005) indicate that there is significant decline at the level of agreement between users and staff concerning the

presence of need or not at several domains and whether the need is met or unmet. The total number of needs seems to be quite stable as Wiersma et al. (2009) argue. Additionally, they state that patients in community care have on average four to eight needs for care a number "unrelated to gender, age or education but does appear to be related to number of symptoms, diagnosis and treatment setting (higher in inpatient care or among homeless people)". The body of evidence also argues that one out of two to four needs appears to be unmet particularly to the domains of psychological distress, daytime activities, social relations and psychotic symptoms. The importance of psychological distress as a predictor of suicide to individuals with Severe Mental Illness (SMI) led Andrade et al.(2016) to conduct a separate research using only the properties of subjective distress and its covariates in a representative sample of 401 outpatient users with a SMI in Brazil. The reported distress as a need was recorded by 165 (41%) patients, being met in 78 (20%) and unmet in 87 (22%). The statistical analysis of the above research showed that presence of distress as a need was predicted by attendance at psychotherapy, presence of suicidal ideation, non-attendance at psychosocial rehabilitation and higher psychopathology.

It is very important to understand what the above differences at level of agreement as well as the indication of certain unmet needs stressed by users mean to therapeutic goals and mental health care provision. The value of user participation is largely based on the following issues according to Stefanatou et al. (2014): 1) the user assessment provided valuable information for treatment planning, 2) the unmet needs that emerged using CAN either provided important evidence on the currently provided treatment or provided useful information to the service and the professionals concerning the users' needs that needed a kind of intervention. Consequently unmet needs are a treatment outcome criterion for the effectiveness of interventions.

Slade et al. (1998) as well as Hansson et al. (2001) argue that the staff usually stressed the needs concerning the symptoms of the disorder such as "psychotic symptoms" or "psychological distress" while patients recognized domains of need relating to their "social functionality" such as "company, social relations, sexuality and daytime activities". Slade et al. (1998) emphasize the emerging evidence of the outcome data rated by service users as being more important than those rated by staff. In the study they conducted in South London (N=137 users with an ICD-10 diagnosis of a psychotic disorder) the results showed that staff rated service users as having an

average 6.1 needs contrasting the result of service users' rating who rated an average of 6.7 needs (p=0.011) and staff ratings of 1.2 unmet needs while users rated themselves 1.8 unmet needs (p<0.001).

Another longitudinal research led by Mike Slade (Slade et al., 2004) investigated the relationship between patient-rated unmet needs and subjective quality of life (N=265) *"higher baseline quality of life was associated with being male, a diagnosis of psychosis, higher disability, higher satisfaction with care, fewer staff-rated or patient-rated unmet needs, and fewer patient-rated met needs"*. The concluding remark of the above research argues that improved quality of life can be achieved through "*actively assessing and addressing patient-rated unmet needs"*.

On the issue of using unmet needs for care as an outcome criterion for the effectiveness of mental health services interventions, Wiersma et al. (2009) conducted a longitudinal research (N=320) suing CANSAS among users as well as clinicians. The aim of the study was to assess the sensitivity to change in unmet needs overtime and the concordance between user and clinician ratings and their relationship with treatment condition. The main results that this research provided argued that the total number of met needs remained quite stable, but unmet needs decreased significantly over time, according to users and clinicians. Specifically unmet needs decreased significantly from 2.0 to 1.5 and the proportion of users who did not mention unmet needs increased from 34% to 39.1%. The highest prevalence of unmet needs was for domains that abovementioned research confirms as well; i.e. intimate relationships, company, psychological distress, daytime activities and physical health.

Part II. Personal contribution

2. Population and Methodology

2.1 Research Sample

The sample of our study consisted of one hundred and eleven (111) users with a severe mental illness and staff members/professionals who were appointed as persons of reference for those users. The diagnosis of schizophrenia or bipolar disorder was given according to ICD-10. The inclusion criteria of the users in the sample of the study were: age between eighteen (18) and sixty five (65) years old and stable clinical condition for a period of at least 3 weeks before the study. The exclusion criteria were: history of traumatic brain injury, neurological disorder or infection of the Central Nervous System, diagnosis of intellectual disability as they are defined by ICD 10.

The sample recruitment took place at the whole eligible network of users of Psychosocial Rehabilitation Units of EPAPSY[1] along with Eginition University Hospital and a PSR Unit of UMHRI. The sample was spread in Athens, Central Greece and Northern Greece.

2.2 Power analysis

Power analysis for the κ coefficient indicated that the sample size of 111 patients was adequate for power or 0.90 and significance level of 0.05, under the null hypothesis of

[1]The Association for Regional Development and Mental Health - EPAPSY is a nongovernmental, non-profit organization, which operates in the field of psychosocial rehabilitation and mental health promotion. It was founded by the Prof. of Social Psychiatry Stelios Stylianidis in 1988. EPAPSY was founded with the joint purpose of a) promoting mental health in regional Greece and urban city centres, b) advancing scientific knowledge through research and training, c) implementing and disseminating innovative interventions according to evidence-based practices in the fields of social psychiatry and psychosocial rehabilitation and d) promoting human rights of people with mental disabilities.

EPAPSY currently serves approximately 2.272 mental health users and family members. It employs 206 mental health professionals, psychologists, psychiatrists, social workers, carers, administrative staff, and clinical supervisors. All employees receive frequent in-house training to continuously improve the quality of rendered services.

κ=0 and the alternative κ=0.4 (Flack, Afifi, Lachenbruch, & Schouten, 1988). The power drops to 0.5 for sample size of 20 participants. Therefore, the results should be taken with caution at items with less than 20 responses. Similarly, power analysis for the ICC indicated that the sample size of 111 patients was adequate for power or 0.99 and significance level of 0.05, under the null hypothesis of ICC=0 and the alternative ICC=0.5 and drops to

2.3 Instruments

2.3.1 Camberwell Assessment of Need

This research demanded the use of the Camberwell Assessment of Need. The CAN was translated in 1996 (Simos, Papageorgiou et al.) and validated in Greek in 2013 (Stefanatou et al., 2014). The research version is available in both clinical and research practice as well in Greek.

Items of the CAN-R in the Original and the Greek Version	
Original Version	Greek Version
Accommodation	Κατοικία
Food	Διατροφή
Looking after the home	Φροντίδα σπιτιού
Self-care	Φροντίδα εαυτού
Daytime activities	Ημερήσιες δραστηριότητες
Physical Health	Σωματική υγεία
Psychotic symptoms	Ψυχωτικά συμπτώματα
Information on condition and treatment	Πληροφορίες για τη νόσο και τη θεραπεία
Psychological distress	Ψυχολογική δυσφορία
Safety to self	Ασφάλεια εαυτού
Safety to others	Ασφάλεια για τουςάλλους
Alcohol	Χρήση αλκοόλ
Drugs	Χρήση ουσιών
Company	Συντροφιά
Intimate relationships	Διαπροσωπικές σχέσεις

Sexual Expression	Σεξουαλική ζωή
Child care	Φροντίδα παιδιών
Basic Education	Βασική εκπαίδευση
Telephone	Τηλέφωνο
Transport	Μετακίνηση
Money	Χρήματα
Benefits	Προνοιακά Επιδόματα

CAN was constructed to assess at an individual level the complex clinical, social and basic human needs of people with Severe mental illness. CAN allows the need assessment on behalf of the user and the staff/health professional concerning the user. It is administered in the form of a structured interview separately for the user and the staff member.

There are two versions; the CAN-R used for research for need assessment and CAN-C used for routine need assessment in clinical practice. As we have already mentioned the CAN-R was validated in Greece so this is the scale that we also used in our research and assesses 22 areas of need as described at the above table.

CAN has a stable structure for all areas of need and the process of need assessment includes four separate sections. The First Section assesses whether a need exists at each of the above areas including relevant questions for severity of need that users or staff cope with. The answers are rated from 0 to 2 as follows:

The CAN severity ratings and the relevant indications for need status	
CAN severity rating	Indication of need status
0 = No problem	No need
1 = No/moderate problem due to help given	Met need
2 = Serious problem	Unmet need
9 = Not known	Unknown

We have focused on the first section of CAN-R at this research which provides us with:

a) Total number of needs (met and unmet)

b) Total number of met needs

c) Total number of unmet needs

CAN is based on several principles as clarified by Phelan et al., (1995). Needs are universal yet individuals with severe mental illness will have the same exact needs on top of others specific additional needs which are related to the illness. As the majority of individuals with severe mental illness have multiple health and social needs which are often neglected at mental health care provision. CAN aims at screening for the existence of needs that are thus neglected by health or mental health professionals while clarifying the severity of need as perceived by users themselves and by the staff members. Lastly, need assessment is used as an integral part of a mental health service evaluation and specifically as an outcome indicator since there is growing evidence that subjective perception of need impacts on the quality of life, the functioning and the psychopathology that is expressed by the mental health service user (Antonio Lasalvia et al., 2005; Wennström, 2008; D Wiersma, 2006).

2.3.2 WHOQOL-BREF

The Greek version of WHOQOL-BREF is the short form of the questionnaire WHOQOL-100. It is an instrument for subjective assessment of quality of life which was developed by the World Health Organization in 1990 (WHOQOL Group, 1998, Saxena et al., 2001, Skevington et al., 2004). The choice for WHO-QOLBREF was initially made by Stefanatou et al. (2014) as an external criterion for evaluating concurrent validity of CAN since it is an indicator of subjective evaluation like the CAN.

WHOQOL-BREF Greek version includes the initial 26 questions of the original and 4 extra items which have been added based on the cultural adaptation and the evaluation of the psychometric properties of the questionnaire (Ginieri-Coccossis et al., 2012). The 26 questions of WHOQOL-BREF, scored at a 5 point Likert scale, study the same dimensions of quality of life that are evaluated in WHOQOL-100 and constitute 4 sections; (a) Physical health, (b) Psychological wellbeing, (c) social relations and (d) environment. The 4 extra questions study the following dimensions: (a) nutrition, (b) social life, (c) family life and (d) work satisfaction. Additionally, WHOQOL-

BREF has two items that study separately according to the patient's perception: (a) the overall quality of life and (a) the general health condition.

2.3.3 WHODAS 2.0

This instrument is the scale developed by the World Health Organization (WHO, 1999, Epping-Jordan, 2000) which evaluates functionality and disability. The Greek version of WHODAS 2.0 and its 36 items includes the original items where the current functionality and disability are studied in the following domains (Üstün, 2010): understanding and communicating, getting around, self-care, getting along with people, life activities and participation in society. The above 36 items are scored at a 5 point Likert scale. WHODAS 2.0 produces scores which are domain-specific for the aforementioned domains. The evaluation of WHODAS provides crucial information which can be made good use of in (a) needs recognition, (b) selection of suitable interventions according to users' needs and capabilities, (c) systematic study of functionality and (d) evaluation of treatment effectiveness. WHODAS 2.0 was chosen by Stefanatou et al. (2014) as an external criterion for the evaluation of concurrent validity of CAN since it is an indicator of subjective assessment of disability and the needs assessment is conducted taking into consideration the handicap of the user.

2.3.4 PANSS

Psychotic symptoms were evaluated using the clinical instrument of Positive and Negative Syndrome Scale (Kay, Fiszbein& Opler, 1987). It is a scale to assess clinical symptoms of schizophrenia. The scale is an adaptation of earlier psychopathology scales, including the Brief Psychiatric Rating Scale (BPRS) as Gottlieb, Xiaoduo and Goff (2010) emphasize. PANSS includes 30 items on three subscales: 7 items covering positive symptoms, 7 items covering negative symptoms and 16 items covering general psychopathology. The PANSS as the abovementioned researchers stress was conceived as an operationalized instrument that provides balanced representation of positive and negative symptoms, as well as mood and anxiety symptoms. All the items are scored at a 7 point Likert scale ranging from 1 to 7. PANSS scale as well as the semi-structured interview for its' evaluation (SCI-

PANSS) have been adapted for the Greek population (Lykouras, Botsis, & Oulis, 1994).

2.4 Data Collection

The study was approved by the Ethics Committee of the 1st Department of Psychiatry, University of Athens, the University Mental Health Research Institute (UMHRI) and the Association of Regional Development and Mental Health (EPAPSY) in Athens. A total number of 111 user-staff pairs were consecutively recruited from the above Organizations. 31 users were treated in Eginition Hospital units (8 in inpatient psychiatric wards, 13 in a day-hospital and 10 in a community mental health centre) and 22 users attended the UMHRI rehabilitation unit. EPAPSY provided us with the whole network of residential units and day center. In total number 58 users were attending the Day Center of EPAPSY or living at a residential unit. Of the total 58 users; 14 users attended the Day Centre of EPAPSY, 19 were living in long term residential units in Athens (out which 10 living at the long term residential unit of Likovrisi Attica, 3 living at the long term residential unit of Penteli Attica, 6 living at the community home in Chalandri, Attica), 18 were living at Central Greece (7 at the long term residential unit of Livadeia, 7 living at the long term residential unit of Chalkida, Evia, 4 were living at the hostel in Chalkida, Evia), 7 were living at Northern Greece (3 at the long term residential unit of Lamia and 4 at the long term residential unit of Trikala). Of the total sample (N=111), 66 users were living at a PSR residential unit while 45 were living at their own home, either with family or by themselves.

The participating users and professionals/persons of reference were informed for the scope of the study and the evaluation. It was clear to all participants that anonymity and confidentiality would be provided and ensured. Once everyone declared his/her interest to participate, the full informed consent of the participants was obtained through written form before the evaluation process began.

For interrater reliability of the evaluation CAN, four evaluators, clinical psychologists experienced in the care of individuals with severe mental illness educated in using the CAN participated at the first interviews in pairs of two. The 1st evaluator conducted the interview while the 2nd was silently present in the process scoring the instrument with no contact of the 1st researcher. The interviews of the staff and the users were

separately conducted. The distance between the user interview and the staff member was no more than 5 days.

Those researchers also evaluated the users with WHOQOL-BREF and WHODAS 2.0 at the same time the CAN interview was taken. To evaluate the relation between needs and psychopathology, a trained psychiatrist would conduct the PANSS evaluation at a distance no more than 1-7 days from the CAN interview.

Socio-demographic characteristics, diagnosis and other clinical information were obtained by the patients' records in collaboration with the scientifically responsible for the unit. Demographic characteristics were obtained concerning age, gender, years of education, current working status, family status and social security. The medical records provided information on diagnosis, psychiatric history of hospitalizations, current mental status, duration of illness, number of previous hospitalizations, con-current physical illnesses and medication information.

2.5 Statistical Methods

The descriptive indices are presented for the variables, namely frequencies and percentages for the categorical variables, and means and standard deviations for the numerical ones. Pearson correlations are computed among symmetrical numerical variables and Spearman's correlations among skewed variables. T-test was used for differences in the means of normally distributed variables whilst Wilcoxon and Mann Whitney non parametric test were used in the case of skewed variables. Chi square was (χ^2) was used to explore associations between categorical variables.

3. Results

3.1 Sample and demographic characteristics

The sample consists of 111 patients, whose demographic characteristics are presented in Table 1 and graphically in Diagrams 1 to 6 (separately by gender). There was no significant difference between genders in age (t-test: t_{105}=-1.563, p-value=0.121), years of education (Mann Whitney: Z=-0.293, p=0.769), marital status (Monte Carlo χ^2=4.3,p=0.111), hospitalization (χ^2=0.723, p=0.395) and number of hospitalizations (Mann Whitney: Z=-0.763, p=0.445). Due to low frequencies in the job status categories (please see Table 1), they were merged into "currently working" or "currently not working". The percentage of the males currently working (23.5%) was significantly higher (χ^2=5.42,p=0.020) than the percentage of females currently working (3.6%).

Age	***Mean***=43, ***sd***=12, ***range***=20-66		
Years of education	***Mean***=12, ***sd***=3, ***range***=6-18		
		N	**%**
Gender	***Males***	74	66.7
	Females	37	33.3
Job status	***Permanent position***	13	11.7
	Temporary position	4	3.6
	Unemployed	51	45.9
	Retired	25	22.5
	Student	2	1.8
	No profession	1	.9
	No reply	15	13.5
Marital Status	***Single***	90	81.1
	Married or in a relationship	7	6.3
	Divorced or widowed	14	12.6
Hospitalised	***Yes***	86	77.5
	No	11	9.9
	Unknown	14	12.6
Number of hospitalisations	***Median***=2, ***Mode***=1, ***range***=1-15		

Table 1: Sample demographic characteristics (N=111).

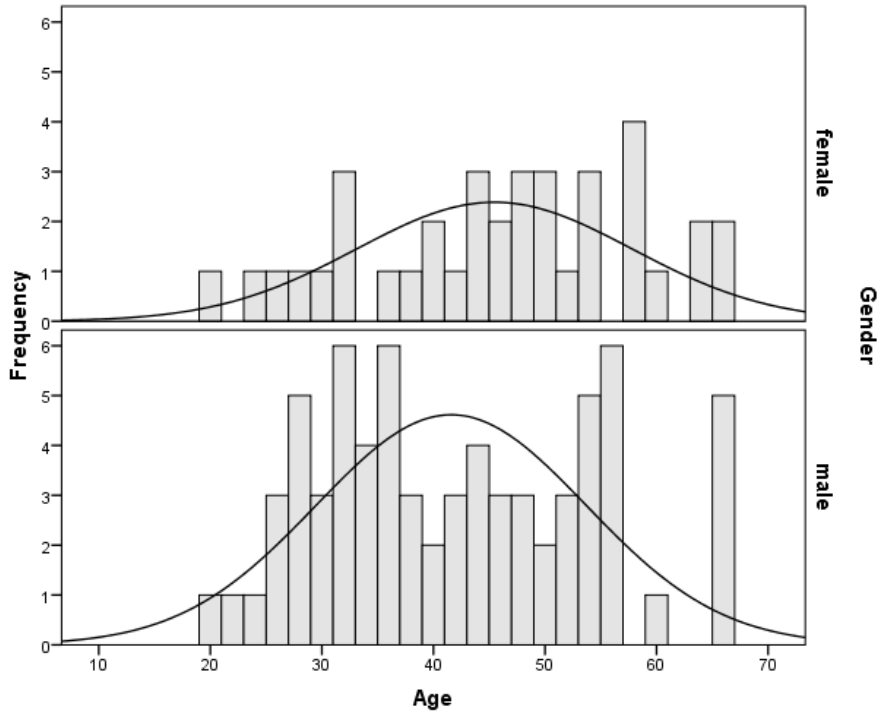

Figure 1: Age distribution by gender

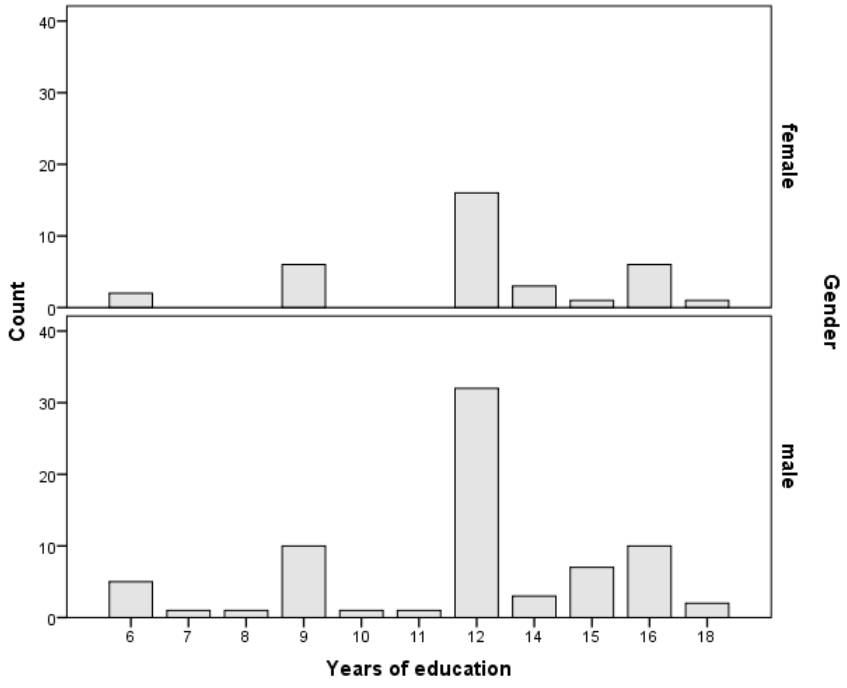

Figure 2: Years of education by gender

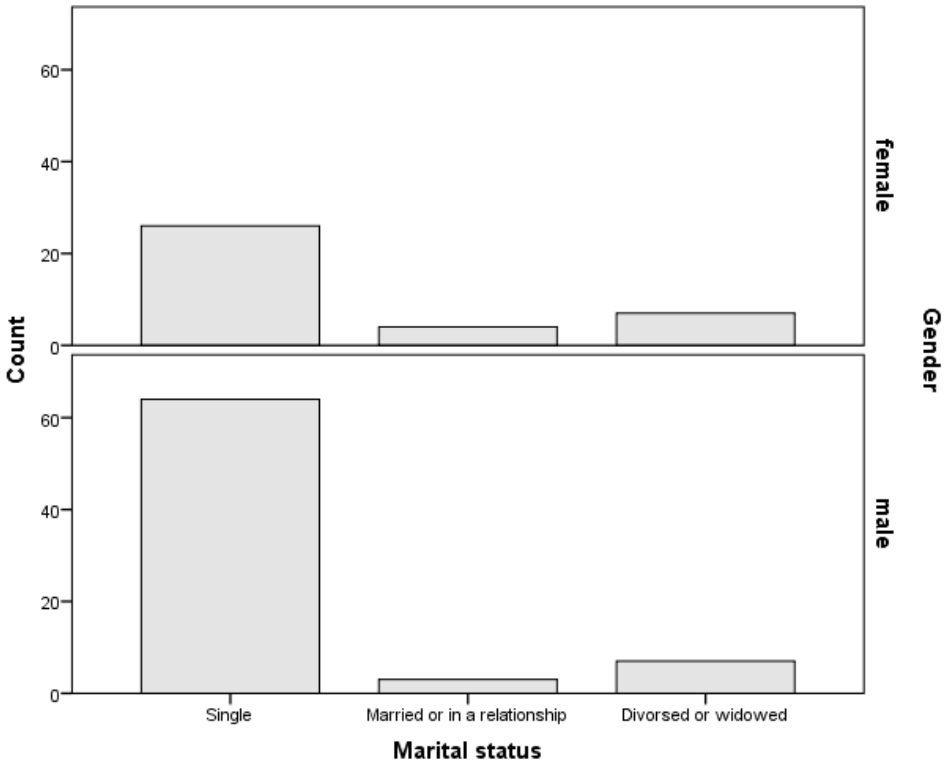

Figure 3: Marital status by gender

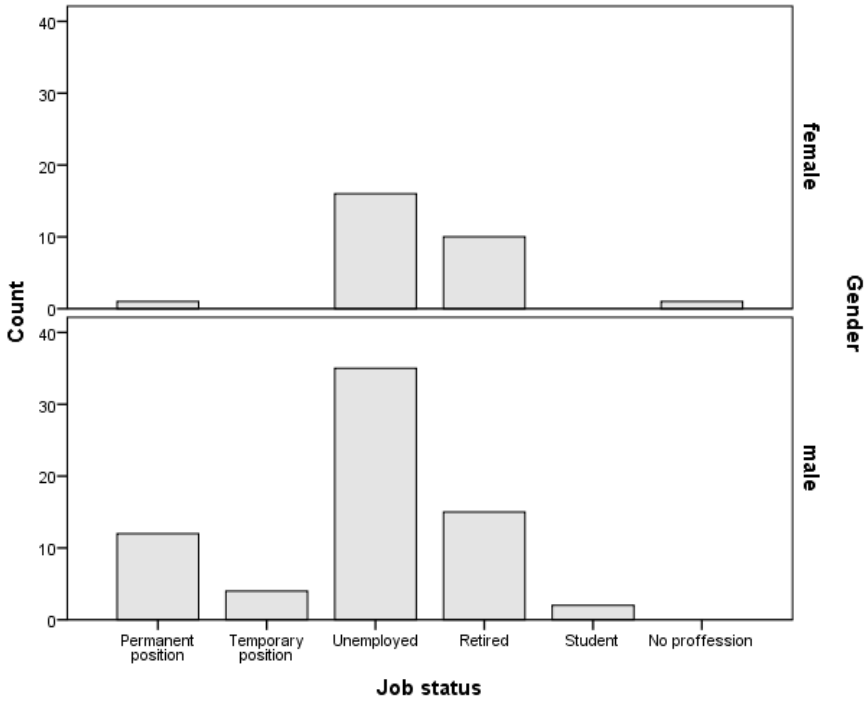

Figure 4: Job status by gender

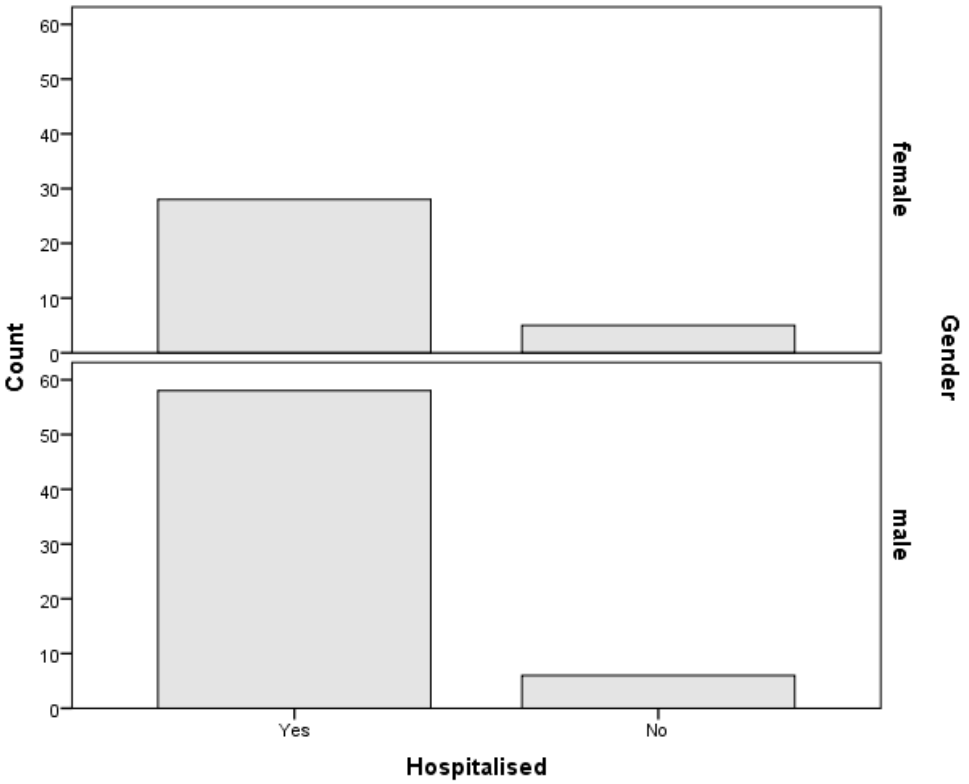

Figure 5: Hospitalisation by gender

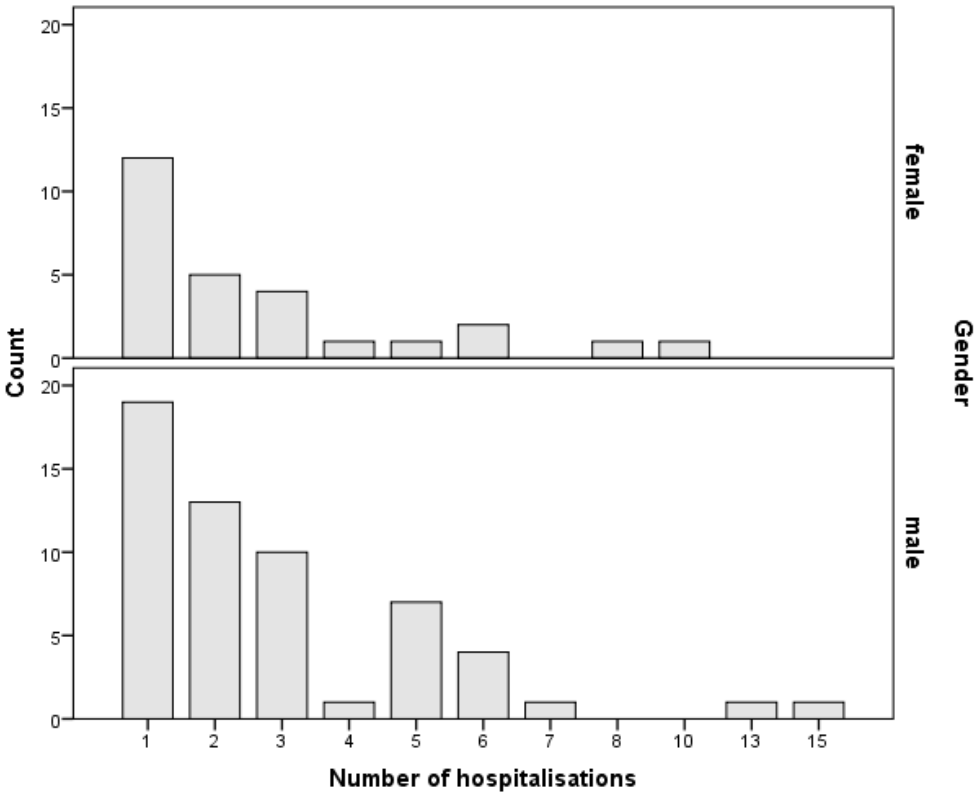

Figure 6: Number of hospitalisations by gender

3.2 Profile of Unmet and Met needs of the patients

Here we present the met, unmet and total (met plus unmet) needs of the patients, both according to their own reports (denoted by u: users) and according to the staff members' repots (denoted hereafter by s: staff). Table 2 presents the descriptive characteristics by informant (user of staff) and Figure 7 depicts them separately. There were no significant differences between informants in the reported met (Wilcoxon: Z=-01.131, p=0.258), unmet (Wilcoxon: Z=-1.530, p=0.126), and total needs (Wilcoxon: Z=-430, p=0.667).

Table 2: CAN needs by users and staff members

		N	*Mean*	*SD*	*Median*	*Min*	*Max*
CAN	Total needs (u)	110	7.9	3.1	8	0	15
	Total met needs (u)	110	6.3	2.7	6	0	13
	Total unmet needs (u)	110	1.6	1.9	1	0	8
	Total needs (s)	108	7.6	2.9	8	1	16
	Total met needs (s)	108	6.2	2.6	6	1	16
	Total unmet needs (s)	108	1.4	1.9	1	0	10

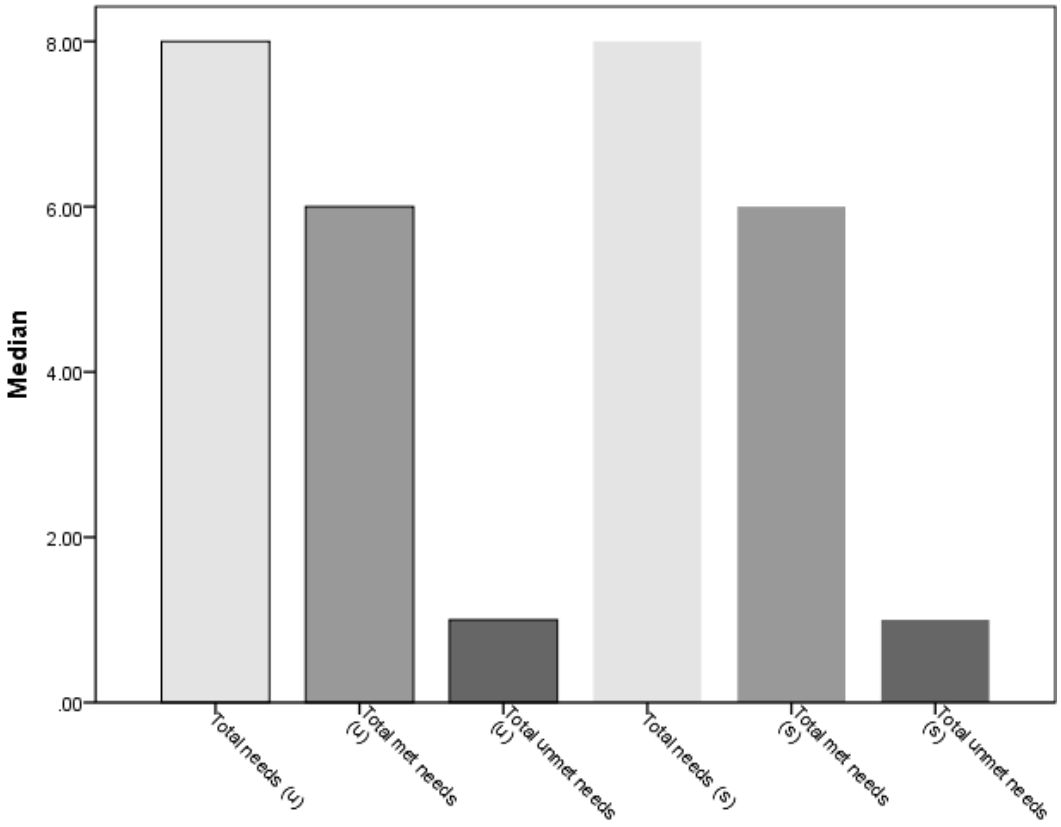

Figure 7: CAN needs

As presented in Table 3, the CAN scores did not correlate with the number of hospitalisations (for those who have been hospitalised at least one time) and the years of education. However there were low but significant, negative correlations of age with the total unmet needs (reported by either users or staff members).

Table 3: Parametric (Pearson) and non-parametric (Spearman) correlations of CAN scores with age, years of education and number of hospitalisations

	Age			**Years of education**			**Number of hospitalisations**		
	Pearson R	**p-value**	**N**	**Spearman r**	**p-value**	**N**	**Spearman r**	**p-value**	**N**
Total needs (u)	-0.1	0.182	106	0.1	0.303	107	0.1	0.362	83
Total met needs (u)	0.0	0.878	106	0.0	0.803	107	0.1	0.476	83
Total unmet needs (u)	**-0.2**	**0.020**	106	0.0	0.756	107	0.1	0.628	83
Total needs (s)	-0.3	0.007	104	0.0	0.799	105	0.1	0.445	82
Total met needs (s)	-0.1	0.218	104	0.0	0.989	105	0.0	0.744	82
Total unmet needs (s)	-0.2	0.014	104	0.0	0.917	105	0.1	0.286	82

CAN total needs and met needs were significantly different between genders according to users' reports (Table 4 –Figure 8), with female users reporting more needs.

Table 4: CAN scores by gender

	Gender												**Comparison**	
	Female						***male***							
	N	***Mean***	***sd***	***Median***	***min***	***max***	***N***	***Mean***	***sd***	***Median***	***min***	***max***	**Z**	**p-value**
Total needs (u)	37	9.3	3.0	**10**	1	15	73	**7.2**	2.9	7	0	13	-3.584	**<0.001**
Total met needs (u)	37	7.8	2.9	8	1	13	73	5.6	2.3	5	0	11	-4.151	**<0.001**
Total unmet needs (u)	37	1.5	1.6	1	0	5	73	1.6	2.1	1	0	8	-0.37	0.711
Total needs (s)	36	7.8	2.9	7	2	16	72	7.5	2.9	8	1	13	-0.226	0.821
Total met needs (s)	36	6.6	2.8	6	2	16	72	6.0	2.5	6	1	11	-0.512	0.609
Total unmet needs (s)	36	1.2	1.3	1	0	5	72	1.6	2.1	1	0	10	-0.186	0.852

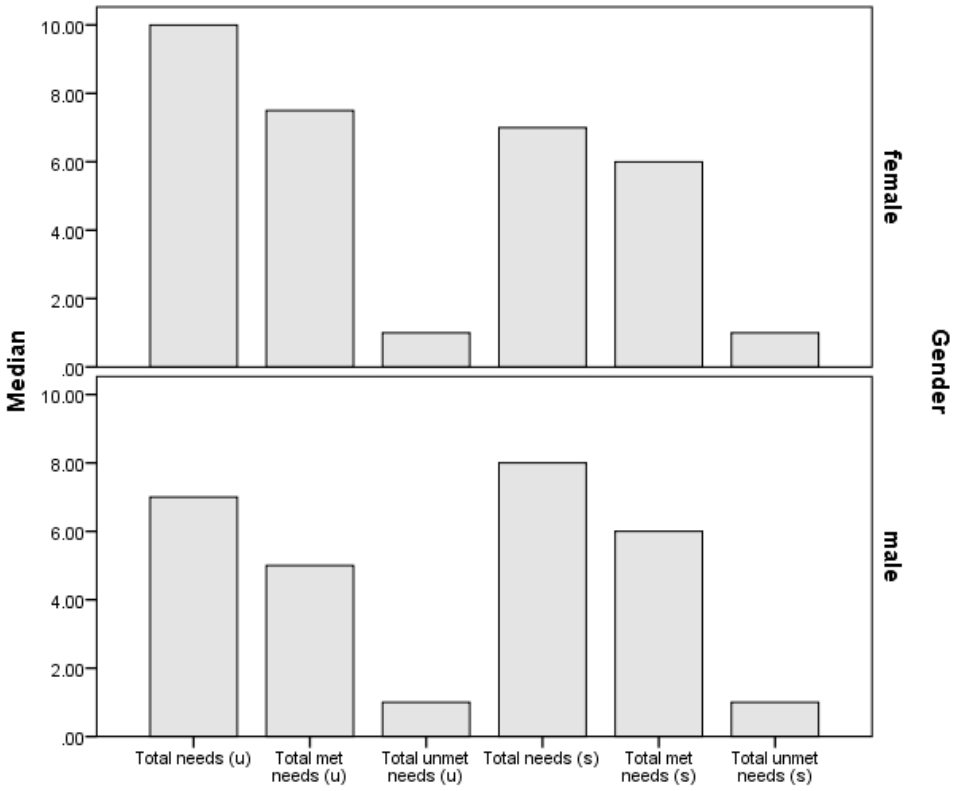

Figure 8: CAN scores by gender

CAN and met needs were significantly different between currently working users and not working according to users' reports (Table 5 –Figure 9), with not working users reporting more needs.

Table 5: CAN scores by job status

	Currently working												Comparison	
	No						Yes							
	N	*Mean*	*sd*	*Median*	*min*	*max*	*N*	*Mean*	*sd*	*Median*	*min*	*max*	Z	p-value
Total needs (u)	78	8.0	2.8	8	2	15	17	7.2	3.5	8	0	12	-0.66	0.509
Total met needs (u)	78	6.5	2.5	**6**	2	13	17	4.7	2.4	**5**	0	9	**-2.559**	**0.010**
Total unmet needs (u)	78	1.5	1.9	1	0	7	17	2.5	2.6	3	0	8	-1.205	0.228
Total needs (s)	76	7.5	2.9	8	1	14	17	7.8	2.8	9	2	12	-0.585	0.558
Total met needs (s)	76	6.0	2.3	6	1	12	17	5.6	2.9	6	1	11	-0.596	0.551
Total unmet needs (s)	76	1.4	1.6	1	0	6	17	2.2	2.9	1	0	10	-0.5	0.617

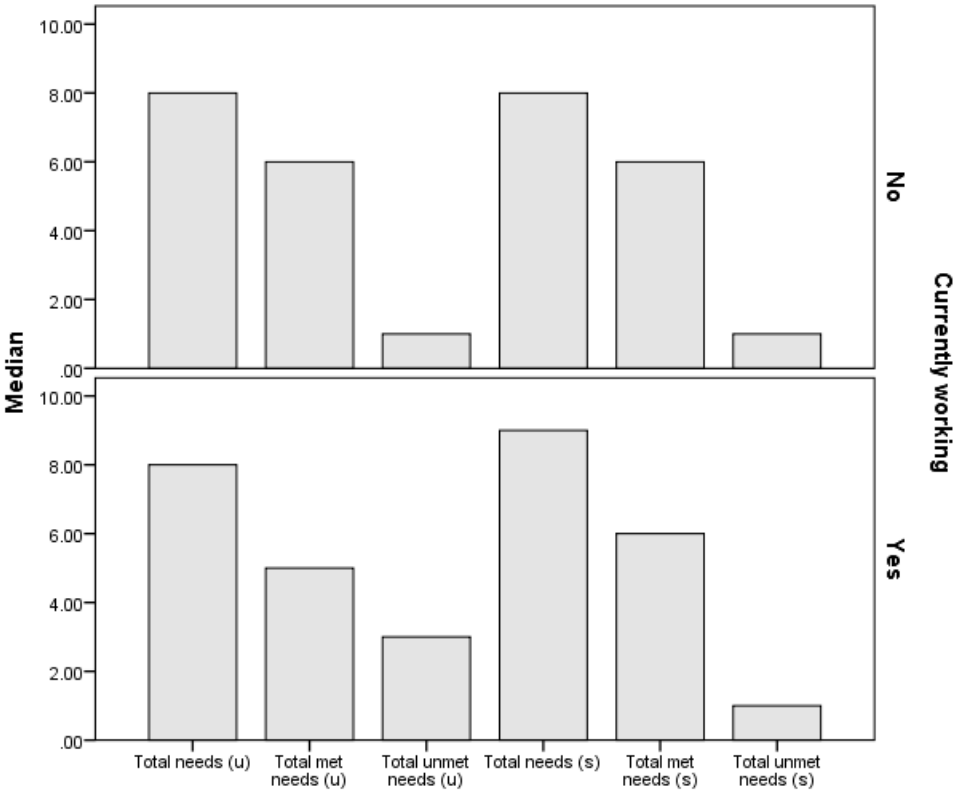

Figure 9: CAN scores by job status

There were no significantly different scores in relation to hospitalization (Table 6 – Figure 10).

Table 6: CAN scores by hospitalisation

	Hospitalized												Comparison	
	Yes						No							
	N	*Mean*	*sd*	*Median*	*min*	*max*	*N*	*Mean*	*sd*	*Median*	*min*	*max*	Z	p-value
Total needs (u)	85	7.6	3.2	8	0	15	11	8.5	2.1	8	5	12	-.915	0.360
Total met needs (u)	85	6.3	2.8	6	0	13	11	7.0	2.2	8	3	10	-1.002	0.316
Total unmet needs (u)	85	1.4	1.8	1	0	7	11	1.5	1.9	1	0	6	-.291	0.771
Total needs (s)	84	7.5	2.8	8	1	14	11	8.5	2.7	8	5	13	-.807	0.419
Total met needs (s)	84	6.1	2.5	6	1	12	11	7.3	2.1	6	5	11	-1.354	0.176
Total unmet needs (s)	84	1.3	1.6	1	0	6	11	1.2	1.5	1	0	4	-.136	0.892

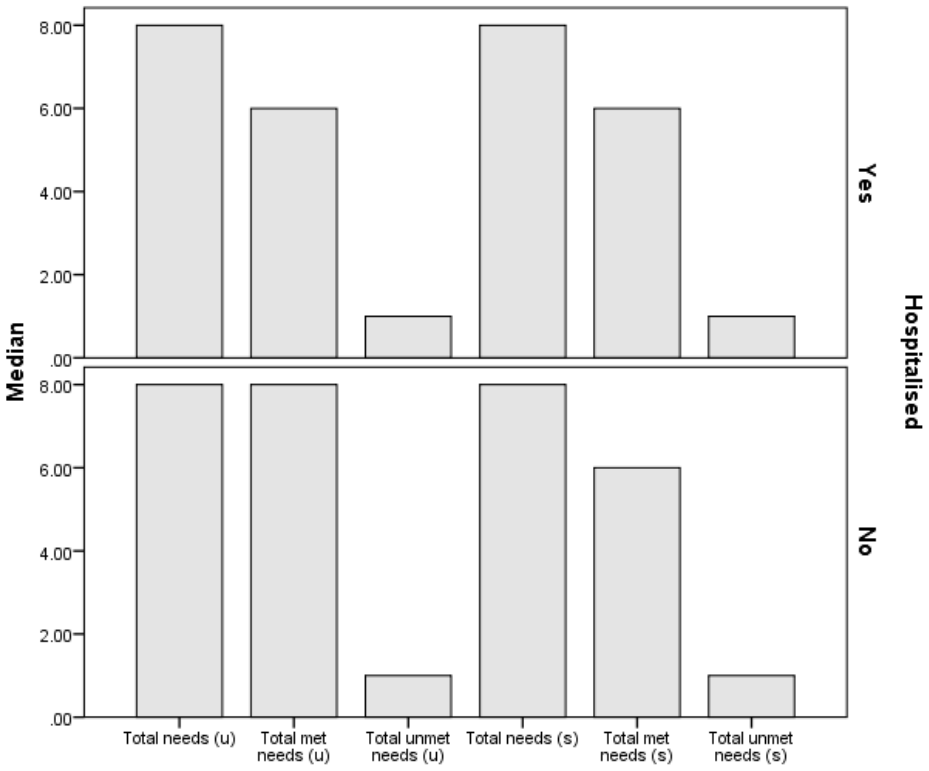

Figure 10: CAN scores by hospitalisation

3.3 Staff and user ratings (%) of level of need for section 1 items of the CAN (n=111)

For the items in section 1, the percentage of patients that were identified (by staff or by themselves) with either no need, met or unmet needs are presented previously in Table 2. Regarding the staff ratings, a need was identified most often in accommodation (77.5%), psychotic symptoms (72.1%), psychological distress (58.5%), and intimate relationships (54.9%). With regard to serious unmet needs the highest percentages appeared in interaction with the environment needs, namely: intimate relationships (19.8%), company (19.8%) and sexual expression (18%).

The ratings by users themselves were well comparable with the ones made by the staff, identifying more or less the same needs. Interestingly a high percentage of the users identify as serious unmet need the psychological distress (19.8%) while the staff considered this need as unmet only in the 10.8% of the cases.

Table 7 Staff and user ratings (%) of level of need for section 1 items of the CAN n=111)

CAN items (section 1)	**No need (%)**		**Met need (%)**		**Unmet need (%)**		**Unknown (%)**	
	User	**Staff**	***User***	**Staff**	***User***	**Staff**	***User***	**Staff**
Accommodation	**27.9**	**19.8**	68.5	69.4	2.7	6.3	0.9	4.5
Food	41.4	45	55.9	45.9	1.8	5.4	0.9	3.6
Looking after the home	54.1	49.5	42.3	40.5	2.7	5.4	0.9	4.5
Self-care	79.3	69.4	18.9	24.3	0.9	2.7	0.9	3.6
Daytime activities	40.5	36.0	49.5	52.3	8.1	9.0	1.8	2.7
Physical Health	58.6	60.4	30.6	27.9	8.1	5.4	2.7	6.3
Psychotic symptoms	**36.0**	**24.3**	55.0	62.2	8.1	9.9	0.9	3.6
Information on condition and treatment	60.4	64.9	27.9	27	10.8	5.4	0.9	2.7
Psychological distress	**33.3**	**37.8**	45.9	47.7	**19.8**	**10.8**	0.9	3.6
Safety to self	82.9	92.8	10.8	4.5	5.4	0	0.9	2.7
Safety to others	89.2	90.1	6.3	6.3	2.7	0.9	1.8	2.7
Alcohol	97.3	93.7	1.8	2.7	0	0	0.9	3.6
Drugs	99.1	95.5	0	0.9	0	0.9	0.9	2.7

Company	47.7	45.0	35.1	29.7	**16.2**	**19.8**	0.9	5.4
Intimate relationships	**38.7**	**37.8**	37.8	35.1	**22.5**	**19.8**	0.9	7.2
Sexual Expression	52.3	47.7	27	19.8	**18.9**	**18**	1.8	14.4
Child care	82.9	83.8	6.3	2.7	0.9	0.9	9.9	12.6
Basic Education	91.0	89.2	6.3	3.6	1.8	3.6	0.9	3.6
Telephone	87.4	86.5	11.7	9.9	0	0	0.9	3.6
Transport	64.0	54.1	32.4	35.1	2.7	2.7	0.9	8.1
Money	46.8	44.1	38.7	40.5	12.6	9.0	1.8	6.3
Benefits	62.2	69.4	18.9	11.7	9.9	3.6	9.0	15.3

4. **Discussion**

Psychosocial rehabilitation services aim to provide mental health services to individuals with Severe Mental Illness. In our research theindividualsthatparticipatedsufferedfromschizophrenia or bipolar disorder which have an early onset (American Psychiatric Association, 2010). Thus the mean number of age was 43 years old with a range between 20 and 66. The fundamental necessary education in Greece is 9 years (6 year Primary School and 3 years Secondary School). Nevertheless as the majority of the Greek population, the sample had a mean of 12 years which is the fundamental education adding 3 years of high school. This is again expected since the first episode of schizophrenia or bipolar disorder takes place at an average age of 21 years.

Another element of socio-demographic characteristics that is important to emphasize is the percentage of unemployment or retired individuals. 45.9% are unemployed and 22.5 % are retired due to the presence of a mental disability. The percentage of unemployment in individuals with a mental health problem is higher than any other disability which shows the social stigma that follows psychiatric diagnosis and symptoms. Heather (2006) argues that sixty-one percent of working age adults with mental health disabilities are not in the active labor force (either unemployed or retired due to mental health status).Additionally, variations according to diagnostic

groups are also noted; the individuals with Severe Mental Illness present the highest percentage typically 80-90% (Murphy, Mullen, & Spagnolo, 2005; Sanderson & Andrews, 2006). At this point it is very important to stress that a certain impairment which leads to a disability does not necessarily mean that the individual with a disability is "unable" to perform a certain action such as joining the workforce. Such a notion does not make any reference in the handicap classification to features of the social world that create the obstacles regardless of the capability of the individual. As Bickenbach, Chatterji, Badley, & Üstün (1999) argue *"it is a classification of limitations of peoples' abilities"*. The same authors criticize the ICIDH model which *"does not clearly acknowledge that the presence of social barriers and the absence of social facilitators play any sort of role in the creations of the disadvantages that a person with a disability experiences"*. Social stigma which places a major obstacle in the employment of users is rated at the research and will be presented at the correlations of the CAN with WHOQOL-BREF and WHODAS 2.0 at a later analysis. Concerning the Greek situation, it is important to state that a large number of service users do not enter the workforce because they receive a social benefit that will be lost upon employment regardless of the amount of earnings. This presents a major barrier for many users and families to pursue actively work since a fear of relapse can put the person once again at the position of needing the social benefit which is not easily obtained due to bureaucratic process that takes a lot of time and effort to succeed in. As Paraskevaidou & Katsaliaki(2015) state there are several barriers in the vocational rehabilitations of mental health service users; (a) the negative status of working status in Greece due to socio-economic crisis, (b) the lack of alternative solutions and (c) social stigma and prejudice. Also the difficulty in vocational rehabilitation has been present since the beginning of the Psychiatric Reform since the only means developed by the Government are the Social Cooperatives who offer protected work conditions without removing the social benefits the user is already receiving. Nevertheless Social Cooperatives have only been developed to a 32,73% of the initially set goal limiting opportunities to very few users (Greek Ministry of Health and Social Solidarity, 2010).

As for the low percentage of participants being students it is argued by studies conducted by the National Confederation of Disabled People(2008) that Greek educational system lacks lifelong learning opportunities while it works often as a

means of social exclusion for individuals with disabilities. Two major deficiencies are noted in (a) educational system and (b) educational facilities and suitable structure to assist individuals with disabilities.

Concerning marital status 81.1% were single while 6.4% reported being married or in a relationship and 12.6% divorced or widowed. The alarmingly high percentage of single individuals is in line with the findings of Agerbo et al. (2004) suggesting *"strong long term association between schizophrenia, singleness, disadvantaged socioeconomic position and labor market marginalization"*. The above place a serious note on community integration of the individuals with Severe Mental Illness that largely live in community mental health units. The crucial importance of community integration is explained by Davidson et al., (2005) who emphasized the destructing effects on both life and recovery that can be observed by the exclusion by the community. Since a person does not work or does not enjoy a full social life the experience of being stigmatized, misunderstood, labeled, or rejected is lived at a great cost. As the researchers go on *"Experiences of being labeled or catalogued by the mental health system, having bad things happen to one against one's will (e.g. restraints, hospitalization), being discriminated against based on one's psychiatric history, and then internalizing this kind of stigma against oneself, with the associated features of shame and avoidance, were also particularly painful and damaging to the person"*. The participants of our research were hospitalized at least once at a 77.5% rate while the lack of records was observed for 12.6% of the sample. Hospitalization as explained above can be a serious risk factor with dire consequences on quality of life and community inclusion. Although the median is 2 hospitalizations (which could have lasted a lot of years for participants in Psychiatric Rehabilitation Units) a range between 1 and 15 hospitalizations was recorded.

The total number of needs is in line with other research evidence that indicates a mean number of total needs (SD) approximately at the same levels (Middelboe et al., 2001; Ochoa et al., 2005; M. Slade et al., 1996) as well as supporting the number of needs that are met and unmet. In our study user and staff members identified approximately the same number of total needs (u: 7.9, s: 7.6), total met needs (u: 6.3, s: 6.2) and total unmet needs (u: 1.6, s: 1.4). Such evidence indicates that users do not overrate their total level of need when they are actively involved in assessment and evaluation (M. Slade et al., 1996). In our research the level of agreement is particularly high with no

significant differences at the total number of assessed needs. Several studies indicate the lack of agreement among users and staff members in need assessment. Arvidsson (2001) states that staff rated more needs, both met and unmet, in nearly all areas. Hansson et al., (2001) also state that key workers identified slightly more needs with a significant difference (s: 6.17, u: 5.76). Hansson et al., (2003)also suggest a statistically significant higher number of reported needs by staff member while stating that having more unmet needs correlated with a worse overall subjective quality of life. a Lasalvia et al., (2007)suggest that mental health professionals and users have different perceptions of needs and that users tend to report more needs in domains related to social and everyday life. In their study they also argued that staff members identified higher number of met needs in most of the domains and lower number of unmet needs. The longitudinal character of the study allowed the researchers to assess the number of needs at follow up with no statistically significant change in their number and discrepancies among staff members and users. The researchers stated that a prediction in staff rated needs could be predicted by an improvement in symptoms severity and levels of disability.

However, several studies indicate a substantial agreement between staff members and service users. Macpherson et al., (2003) conducted a study where a high level of agreement between user and staff rating was indicated. It was reasoned as an indication of a deep knowledge of users by their key-workers. Also, it was discussed that staff members might have been influenced in their assessment of need by awareness of users' perceived need since keyworkers conducted both assessments not being blind to what they had already reported. However the study that Stefanatou et al. (2014) conducted as well as our current study involved different researchers who assessed separately keyworker and service user. A high level of agreement between users and staff members was observed in our study which could be explained partly due to the stable relation that users have with their key workers. The major percentage of our sample was receiving services from community mental health units for a period of time that exceeded 6 months and ranged to several years in the residential units. The therapeutic relation that is thus developed allows staff members to understand the perceived need of the user of reference and line with his personal goals as set by individualized care plans and recovery goals that are currently implemented in the Day Center of EPAPSY and the Residential Units of EPAPSY as well. High levels of

agreement were also observed by previous studies as well(A. Lasalvia & Ruggeri, 2007; M. Slade, Phelan, & Thornicroft, 1998).

Concerning other social determinants and how they influence the total number of needs that are reported, as shown in previous studies(Macpherson et al., 2003; McCrone et al., 2001; Wiersma, 2006), years of education was not associated with needs. As shown in other studies the years of education did not correlate with the number of needs (both met or unmet). The same studies did not associate significantly age or hospitalization with reported needs. In our study age was negatively correlated significantly with total unmet needs. As it was indicated social domains of need were reported by users and staff members as an area of unmet needs. The early onset of a SMI can cause great harm in placing major obstacles to a person and his self-fulfillment. As Patel, Flisher, Hetrick, & McGorry, (2007) state poor most mental disorders begin during youth even if they are discovered in later life. *"Poor mental health is strongly related to other health and development concerns in young people, notable lower educational achievements, substance abuse, violence, and poor reproductive and sexual health".* The authors encourage integration of mental health as a major public health challenge with a special focus to younger ages stating that most of their needs remain unmet since no suitable mental health intervention takes place even at high-income countries. Regarding the number of hospitalizations in our study it was not significantly correlated with the reported needs. This data is rather important since we can understand that Greece has an especially high number of involuntary admissions that many times violate human rights of users and are not beneficial for a better mental health status (Stylianidis, Peppou, Drakonakis, & Panagou, 2014). Finding no correlation of hospitalizations with unmet needs or met needs with a range from 1 to 15 hospitalizations is important since we understand that the more hospitalizations take place with no therapeutic outcome the more their character tends to become a measure to "unburden the family" or "protect the rest of society" (Stylianidis, Peppou, Drakonakis & Panagou, 2014). This also shows the lack of continuity of services (E Loukidou et al., 2013) which could support a user from being hospitalized so often.

Following up on CAN scores and the correlation of gender with reported needs, our study suggests that women report more needs in total than men. In line with evidence on mental health service use (Wang et al., 2007) sex is significantly related to service

use with women more likely to use services than men. Leaf & Bruce, (1987) explaining the relation of gender and service use argue that women are more likely to use health services with positive attitudes while men are less likely to use those services and when they do their attitude will be negative in most cases. Data from an epidemiologic research in a rural area of Greece (Stylianidis, Pantelidou, & Chondros, 2007) show an underrepresentation of men in the research since they were more reluctant to participate discussing their mental health needs. Also the same research showed increased alcohol abuse in men as a way to deal with hardship than women in line with the international evidence. The World Health Organization (WHO, 2014) reports harmful use of alcohol is the leading risk factor for death in males aged 15-59 years while men also have a greater rate of total burden of disease in DALYs attributable to alcohol than women (m: 7.4%, w:2.3%). Female gender is also a risk factor for developing a common mental disorder while substance use was more common in men compared to women (Skapinakis et al., 2013). We can understand that Greek culture also cultivates the idea of the masculine values of the "macho man" who speaks little of his problems and showing his emotional vulnerability can be a sign of weakness. As Eagly & Mladinic, (1994) state the evaluative content of the female stereotype tend to be more positive and allowing vulnerability in contrast with male stereotype that label power seeking behavior as a "masculine characteristic". This could partially explain why women expressed more needs than men in our study.

After explaining employment status above we can proceed with discussing our results that CAN score and met needs were significantly different between currently working users and the ones out of the active labor force. Not working users report more total met needs. Lloyd, King, & Moore, (2010) argue that employment status is of crucial importance to recovery in individuals with a Severe Mental Illness. Specifically it is stated that users with some employment had higher score in Recovery Assessment Scale than those who were receiving a social security benefit or pension. The above stresses the importance of work in mental health and the sense of contribution to the society and self that it brings. It is understood that more needs are going to be reported when an individual does not work since he/she will feel more dependent on the public mental health and social security system. Few work opportunities are present for individuals with a SMI in Greece. Other supported forms of employment such as Individual Placement Support model has been implemented for very few pilot

cases (PEAPSEE, 2013) depending on the EU funding that is received. Loukidou et al., (2013) state that only 33% of the originally set goal for Supported forms of work through Social Cooperatives (KOISPE) was achieved in ten years (2001-2010). As the Greek Ministry of Health (2010) states vocational rehabilitation is still lacking in Greece for individuals with disabilities although its promotion could help individuals both in their own goals of recovery as well as be more financially cost effective to "relieve" the public social security system of paying more to benefits.

In our study we used only the first section of CAN which measures the presence of need and the agreement between staff members and users. As we have already shown in the results of the study the major needs that were identified most often are **accommodation (77.5%)**, **psychotic symptoms (72.1%)**, **psychological distress (58.5%)** and **intimate relationships (54.9%)**. Evidence from other studies agree that psychological distress, social relation domains and psychotic symptoms are often among the most commonly reported needs. Nevertheless, accommodation and psychotic symptoms although emphasized by both users and staff members have a high percentage in met need. The units that were involved in our research were mostly community mental health units (Residential Units and Day Centre) where it seems that accommodation is taken care of at a satisfactory level as well as medical attention to positive and negative symptoms of the serious mental illness.

Serious unmet need has been identified by both users and staff members in **company (s: 19.8% - u: 16.2%)**, **intimate relationships (s: 19.8% - u: 22.5%)** and **sexual expression (s: 18.9% - u: 18%)**. Interestingly enough, a major discrepancy that was significantly noticed was in the identification of **psychological distress** as a serious unmet need in users (19.8%) while the staff identified that need as unmet in the 10.8% of the sample. Another smaller disagreement was noted at intimate relationships were 22.5% of the users reported it as serious unmet need while 19.8% of the staff members recognized it as such. As Wiersma & van Busschbach, (2001) argue serious unmet need is a major indicator of insufficient supply of treatment interventions. Unmet need is also considered a predictor of perceived quality of care and in meeting users' needs treatment engagement and outcomes are promoted (Apantaku-Olajide, Ducray, Byrne, & Smyth, 2012). The offered services in community mental health unit seem to be effective in meeting accommodation and psychotic symptoms yet there are no services that tend to needs in the social domain function of the users.

Thus, psychological distress can be assumed that is recognized due to lack of met social functions rather than clinical needs. The staff seems to be recognizing the social needs but they do not consider it as important as the users themselves since more "fundamental" needs are met (accommodation, clinical symptoms). At this point it is important to emphasize the discrepancy that was observed particularly at the psychological distress field. An explanation on this finding could be that staff members usually tend to recognize needs that are directly associated with a specific intervention or service in the public mental health field. Such needs are the accommodation and the support and treatment provided to psychotic symptoms. Nevertheless, as we explained above social functioning fields can be often neglected. The fields that unmet need is recognized by both staff and users at a significant level are those that in other words describe the "social isolation" that users experience. Social isolation has been defined as loneliness by Cacioppo, Hawkley, & Thisted, (2010), low perceived social support (Berkman, 2009) and weak social relationships as (Holt-Lunstad, Smith, & Layton, 2010) argued. Furthermore, Chou, Liang, & Sareen, (2011) argue that social isolation is directly associated with anxiety and thus psychological distress. The importance of sustaining a social network with friends and intimate partners is also emphasized by Cacioppo & Hawkley, (2003) who claim that weak social ties can be a risk factor for morbidity and mortality especially in vulnerable groups; undoubtedly individuals with SMI constitute such a group. The staff members seem that to neglect the psychological distress caused by the above reasons and M. Slade et al., (1996) point out that such discrepancies can derive from the professional values of staff members as well as the principles of the theoretical scientific background that guide them in understanding the user and his needs. On the other hand, users do not seem to mention the "social" needs since they cannot understand what kind of help they could receive on the matter (Slade et al., 1998).

Community integration including social relationships and intimate ones seems to be an issue that is yet to be answered. The crucial importance of community integration is argued by Topor et al., (2006) who emphasize the recovery and life destructing effects that experiences of being stigmatized, misunderstood, labeled, or rejected by one's family due to mental illness can have. Part of the recovery process is the expression of sexuality in individuals with SMI Stylianidis, Belekou, & Farsaliotis (2014) argue. As they also comment sexuality is often repressed in Psychosocial

Rehabilitation Units forming a "silent agreement" to collectively repress this issue. Quinn & Browne (2009) state that sexuality among individuals with SMI is a critical aspect of the personal identity and a legitimate area to be addressed in care. However, it is stated that among the barriers of health professionals is lack of knowledge about sexuality, conservative attitudes and anxiety when discussing sexual issues which are of crucial importance affecting relationships and ongoing commitment to treatment. Sexuality has to be taken into consideration when providing services while as Werner (2012) argues the serious unmet needs of intimate relationships and sexual expression are dictating that effective interventions be designed and evaluated to cater for those personal and social needs of the users.

Werner (2012) argues that our goal should be to attain a satisfactory recovery process and in line with this the CAN should be made an integral part of the service provision process for individuals with SMI and both staff members' and users' perspectives must be taken into account in developing services to meet the assessed needs. Lasalvia et al.(2000) argue that staff members tend to identify more clinical needs than users who focus their attention on social domains and needs pertaining social relationships and intimacy which needs remain unmet. Subjective distress is reported as a major unmet need with a significant difference between users and staff members. As Andrade et al., (2016) indicate, subjective distress is a risk factor for suicidality among individuals with a SMI. Nevertheless it seems that it is often overlooked since the available services target needs of a more biological direction rather than a psychosocial one. The percentage of unmet need in the previous study reached 21.7% approximately close to our results and was predicted by higher psychopathology; higher severity of clinical symptoms indicated higher levels of distress and low quality of life thus effecting directly on social and intimate life. According to Sklar, Groessl, O'Connell, Davidson, & Aarons, (2013) a major step in understanding the unmet needs of the users is to make steps towards a more recovery-oriented service provision introducing measures and interventions which are shaped not by "clinical" or "service-based" defintions according to traditional moderls of mental illness but to implement "service user-based" definitions that *"pertain to the person's leading a meaningful, purposeful life, even in the face of a mental illness"* as Slade, Amering, & Oades, (2008) argue.

It is important to stress that further analysis and correlation between needs and clinical symptom severity as measured by the PANSS has to take place to test the hypothesis that when the user is worse in his clinical symptoms size and satisfaction with emotional and social relations are still an important determinant or less so as Hansson & Björkman (2007) argue. Other research (Birchwood, 2004; Tarrier, Khan, Cater, & Picken, 2007) emphasize the deep psychological or emotional distress following psychosis thus disrupting everyday life and social networks.

5. Limitations of the study

A major limitation of the study is its cross sectional design which does not allow us to use this information as a treatment outcome criterion. Nevertheless, the careful naturalistic planning of the research allows us to re-visit the sample following up on changes in psychopathology correlating with social functionality and subjective quality of life.

Also, due to the fact that approximately 60% of the users who participated in our research live at a PSR Residential unit, the results cannot be generalized to the wider population of individuals with SMI.

Statistical analysis was limited to profiling the total needs (met and unmet) as well as presenting the descriptive indices of those needs (met and unmet). Important work still remains to be done working on correlations with PANSS, WHOQOL-BREF and WHODAS 2.0.

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